



A Caregiver Resource Guide

Reality Check 



OFFICE OF THE GOVERNOR
CHICAGO, ILLINOIS 60601

ROD R. BLAGOJEVICH
GOVERNOR

Dear Caregiver:

More than one million Illinoisans dedicate an average of 20 hours per week caring for seniors, persons with disabilities or small children. These compassionate citizens perform such services out of love and concern for people who need assistance.

Caregivers are seniors who are taking care of their ill spouses; children or grandchildren taking care of their parents or grandparents; or neighbors or friends taking care of seniors in their communities.

Caregivers play a critical role assisting our seniors. They take them to doctors' appointments; they take them shopping or do their shopping for them; they help them pay their bills and balance their checkbooks. Whether it's simple tasks like answering the phone for them, or complicated tasks like dealing with chronic or terminal illnesses, caregivers are compassionate and caring individuals who are there at all times for their older parents, friends or relatives.

In Illinois, the average caregiver is a woman over 50, married, working full time and also caring for at least one child. And many caregivers are older, with health problems of their own.

This packet will provide you with useful information and resources available to Illinois' caregivers. As Governor, I am deeply grateful to all of you for your hard, caring and compassionate work that helps improve the quality of life for your charges.

Sincerely,

A handwritten signature in black ink that reads "Rod Blagojevich".

Rod R. Blagojevich
Governor

Illinois Department on Aging



Governor Rod R. Blagojevich
Director Charles D. Johnson

421 East Capitol Avenue, #100, Springfield, Illinois 62701-1789
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Dear Friends:

How is this for a job description?

Must be willing to work until exhaustion most days. Task involves heavy lifting, inter-personal counseling, bookkeeping and insurance management, housework and laundry, shopping, cooking, light banter and socializing. Ability to talk with family members, doctors and other medical personnel. Must remain calm and pleasant at all times or risk feelings of guilt. No training available before work begins.

This is a description of a caregiver to a person with a chronic, debilitating condition. And no wonder that the caregivers in our state are my personal heroes. I admire them because they have decided that the human bond that connects them to their elder is more important than personal goals of the moment. And I admire them because their choice to care helps maintain the bond between the mature family and the community.

Based on my admiration for caregivers and my concern for their elders, I have asked my staff to put together this resource guide that is designed to be a work in progress. We have put together the latest information available that will be of help to caregivers, along with tips and telephone numbers. The book is designed to be supplemented with a regular issue of information from the Department on Aging.

I hope that this resource guide will serve as viable evidence of our respect for families who care and for the work that they do.

With respect,

A handwritten signature in black ink that reads "Charles D. Johnson".

Charles D. Johnson
Director, Illinois Department on Aging



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#1

Financial Resources

Sometimes, in the rush to provide care and round up resources, caregivers overlook a critical part of the older adult's picture: financial resources. Failure to keep an eye on the bottom line can result in financial disaster. Here's what to consider:

- ☒ **Overall picture.** The older adult's assets will determine the programs for which he or she is eligible. State support like Illinois Cares Rx, the Community Care Program is directly tied to asset level. Circuit Breaker help is based on household income.
- ☒ **Tax breaks.** Is the older adult a property owner? Contact the county assessor to make sure that taxes are paid; then make sure that senior tax breaks are being used. Older adults with high expenses and no need to leave an estate, may wish to explore available tax deferral programs and reverse mortgages.
- ☒ **Review all insurance.** Is Medicare supplement insurance being paid in a timely manner? Is an automatic payment available through the bank? Is the older adult still paying for insurance on a car that is no longer being driven or a boat that was sold? Is property insurance paid up to date? If there is a life insurance policy, do you know where the papers are kept?
- ☒ **Unnecessary expenses.** Check that subscriptions to publications are terminated if they are not being read, as well as memberships and activity fees that are unused.
- ☒ **Utilities.** How are they being paid?
- ☒ **Benefits from former employers.** Call the human resources department of all former employers. Ask for information about all benefits for which the older adult could be entitled. Check to ensure that beneficiaries and addresses are up-to-date.






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Choices for Care

There are a number of services available for gaps in function, usually caused by age-related frailty or disability. Services available in Illinois sustain people of all ages who need assistance to compensate for mental and physical challenges. The services may be paid or unpaid, offered by friends and family, professional caretakers who come to the home or group living facilities or institutions that specialize in a particular type of care. Here are examples of the challenges – and the long-term care services available.

-  **Helping Hands.** A community resident can no longer pass the driving test. A daughter brings in groceries; a niece takes the resident shopping for clothes; while a senior services bus drives the resident to medical appointments. Professionals call this informal support.
-  **Community-based Services or Home Care.** This is the broadest category of care available and usually the most desired by older adults. It can be only a friendly visitor to check on an older adult or a son who comes weekly to pay bills. But it also covers essential support for home care such as durable medical equipment, housekeeping service, personal care and home-delivered meals. It also includes adult day service, activities and usually a meal in a group setting that offers respite to caregivers.
-  **Retirement Communities.** Often apartment buildings or small cottages that typically offer a wide continuum of care, possibly including recreation, meals, van trips for shopping and social outings, housekeeping, emergency assistance and health-care facilities.

- ☑ **Assisted Living Facilities.** Like retirement communities, they are often apartment buildings but they typically offer a menu of personal care. This care varies among facilities. Some offer meals and well-being checks only. Others offer assistance to people who are quite frail, including dressing, bathing, grooming and personal care.
- ☑ **Continuing Care Retirement Communities.** Here is a continuum of care: a combination of independent living, assisted living and skilled nursing care. In most cases, the older adult must enter at the beginning of the continuum and not the end.
- ☑ **Nursing Homes.** This is the care option that is based on a medical model, and it is usually the most expensive category of care. Residents in nursing homes are typically unable to walk or get out of bed unassisted, unable to go the bathroom alone or have a serious cognitive impairment that threatens safety if left alone.
- ☑ **Home Health Care Services.** These services are available to an individual who is at risk of going to a nursing facility due to health-related problems. The services are provided at an individual's home according to a plan of treatment prescribed by a physician. Home Health Services may include the following physician-ordered treatments:
 - ✓ medication supervision
 - ✓ teaching of self-administration of medication with follow-up
 - ✓ observation and recording of vital signs
 - ✓ catheter maintenance
 - ✓ non-sterile dressing changes
 - ✓ medical equipment use
 - ✓ tube feeding
 - ✓ colostomy care
 - ✓ teaching therapeutic diet management and maintenance
 - ✓ teaching use and maintenance of medical equipment
 - ✓ physical therapy
 - ✓ occupational therapy
 - ✓ speech therapy
 - ✓ medical social services
 - ✓ home health aide services.



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Long-Distance Caregiving

Long-distance caregiving is one of the toughest challenges of caregiving. But it is critically important to the well-being of the older adult and has the potential of delaying or minimizing cognitive deficits. The importance of regular communication – to the caregiver and the older adult alike – has resulted in a number of creative responses to physical changes that impede communication.

Here are some of them:

- ☒ **Older adult cannot hear well enough to use a telephone, even if it is amplified.** Buy a role of stamps and start writing again – frequently and regularly. Send cheerful cards. Or, better yet, send old pictures: “Remember the fun we had at this Thanksgiving dinner in 1996, Mom?” Or: simple riddles, brief paragraphs about your observations of daily life or your activities.
- ☒ **Older adult cannot see well enough to read.** Phone daily, at the same time, if possible, so that the older adult will have something to look forward to. See that the older adult makes use of talking books. Record your memories of past events that were fun and send them so the older adult can enjoy your voice, as well as the memories.
- ☒ **Older adult is cognitively impaired.** Hang pictures of loved ones in the room. Make a poster with your picture and a brief message like “I love you” or “Hi, Mom.”
- ☒ **Older adult is beginning to lose touch with community and old friends.** Buy a box of greeting cards. Stamp and address them and encourage your loved one to maintain old ties, and to forge new ones.



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Make Time for Yourself

It sounds trite, but if you are to be an effective caregiver, you must make time for yourself. Part of this involves effective use of the aging network; another part, effective organization.

- ☒ **Get organized.** Draw up a list of all the services needed; then tap resources around your elder. Send postcards to the religious, social and civic organizations that have your elder's name on the roster. Ask if they can provide helpful service. Send similar cards to family members and friends. In a perfect world, you can establish a service chart: Someone to run errands, another to do meals, a friendly visitor in person or by phone, an emergency contact number, and transportation to medical appointments. But, of course, the world is not perfect. Here is good news: the aging network will help fill in the gaps.
- ☒ **Get to know the aging network.** A whole organized, effective relief team exists in your very neighborhood. To learn how to reach this team and the services available to you, write or call the Illinois Department on Aging, 421 E. Capitol Ave., Springfield, Illinois 62701-1789; 1-800-252-8966. For out-of-state caregivers, call the Eldercare Locator at 1-800-677-1116, they will hook you up with resources near your elder who needs care.
- ☒ **Know yourself.** Honestly assess your own needs, strengths and resources. As you manage the needs of the elder in your life, make a similar management plan for yourself. Be sure to include time for medical appointments, your financial affairs and the spirit-lifting time to maintain your ties with civic, social and religious organizations. Tell the groups you belong to about your caregiving responsibilities, and ask for their support. Look at your life picture: Are there some activities that can be eliminated temporarily? This may be a good time to re-focus on the important stuff. Friends are your best ally. Good friends will respond if you ask them to give a hand in little ways. Remember: You are not in this alone.



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Advance Directives

In an effort to provide for their heirs and dependents, many people are careful to purchase instruments of security like insurance. But, according to Illinois experts in social policy and elder rights, the public often fails to discourage another crisis: the critical transfer of authority in case of incapacitation.

In Illinois, an advance directive is a term for the legal documents that allow people to make decisions or express wishes about health care and asset management in the event they become unable to personally make decisions or express their wishes.

Advance directives include:

- ☒ **Power of Attorney for Health Care** — gives a named agent (a trusted friend or family member), the authority to make health care decisions on behalf of one who is incapacitated. The document may be used instead of or together with a Living Will. The agent, who does not need to be an attorney, will speak for the principal and make decisions according to the principal's wishes even when the principal is physically or mentally incapacitated.
- ☒ **Power of Attorney for Property** — gives a named agent the authority to make decisions about assets, finances, bank accounts and other types of property. The agent, who does not need to be an attorney, will speak for the principal and make decisions according to the principal's wishes even when the principal is physically or mentally incapacitated. It must be notarized and witnessed.

- ☑ **Living Will** — gives a doctor the authority to withhold life support if one is terminally ill. It must be signed in the presence of two witnesses who are not related to the signer by blood or marriage and thus might be beneficiaries of the signer's estate, or would financially benefit from the death of the person who is signing the Living Will.

Other useful legal instruments include:

- ☑ **Will** — contains a person's instructions about disposition of property at his or her death. It must be signed and witnessed by two people who are not beneficiaries.
- ☑ **Living Trust** — allows a person to transfer property during his or her lifetime with the trust assets being controlled by the trustee or distributed to the beneficiaries according to the trust document.

Here are some suggestions:

- ☑ Review all of these documents annually.
- ☑ Make several copies of each of the directives you used. Keep the original in a file at your home, a copy in the glove compartment of your car, and give copies to your agent, doctor, lawyer and key family members or friends.
- ☑ Keep a list of all of the people to whom you have given copies.
- ☑ If you travel to other states regularly, make advance directives in those states, as well.

Although most of these documents are valid in other states, that is not always true. Each state is different, so people who travel, "snowbirds" for instance, should comply with the applicable laws pertaining to the above documents in the states where they visit for frequent or lengthy stays.

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All powers of attorney under Illinois state law are now “durable” unless they state otherwise. This means that an agent can act for an incapacitated person during that period of incapacity. However, if you ever change your mind, the documents can be revoked at any time, but the best practice is to revoke the directive by signing a formal, written revocation.

If you do not have an advance directive, the Illinois Health Care Surrogate Act allows family members, friends or guardians to make a broad range of medical treatment decisions on behalf of an incapacitated person who cannot make and communicate personal decisions.

Surrogate decisions, which include decisions about life support, apply only if the treating doctor certifies in writing that the patient lacks the ability to make and communicate decisions about medical treatment. Concurrence is needed by at least one other qualified physician on the issue of incapacity. The law permits the surrogate decision-maker to forego life-sustaining treatment only if the patient is terminally ill, permanently unconscious or diagnosed with an incurable or irreversible, terminal condition that causes severe pain or other inhumane burden for which treatment would provide minimal benefit.

Illinois law also mandates the distribution of property if a state resident dies without a will.

The best approach is to decide on your goals, then consult with a professional who can decide which of these legal tools best achieves those goals.

☒ **Must an attorney prepare these forms for you?** Although Illinois law does not require that an attorney prepare these forms for you, for proper guidance and to protect your own interests, you may choose to involve your attorney anyway.



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Finding the Best Home Care Provider

When older adults need more help at home, there are options that they may not be aware of that the Illinois Department on Aging offers through the Community Care Program. This network of statewide support that has won the admiration of seniors and professional service providers alike.

The maximum asset levels have been raised to allow more seniors to take advantage of the services offered by the Community Care Program. The program offers assistance with household tasks such as cleaning, planning and preparing meals, doing laundry, shopping and running errands. Homemakers also assist seniors with personal care tasks such as dressing, bathing, grooming and following special diets.

Here is how to go about finding the best care.

- ☒ **Exactly what services are needed?** Take your time answering this question. Examine the needs of the senior.
- ☒ **Is there a need for personal care?** Does the older adult need assistance with things such as bathing, grooming, dressing or help with following a special diet?
- ☒ **Is there a need for assistance with household tasks?** Does the older adult need assistance with things such as cleaning, planning and preparing meals, doing laundry, shopping and running errands?

This information will be helpful in finding the correct agency that best fits the needs of the senior.

- ☑ **Develop a list of home-care agencies in your community.** You can identify these agencies by calling the Illinois Department on Aging Senior HelpLine at 1-800-252-8966, your Area Agency on Aging, or the Case Coordination Unit in your area. Or, if you are a long-distance caregiver, call the Eldercare Locator at 1-800-677-1116.
- ☑ **Ask about credentials and training the agency requires of its employees.** The Illinois Department on Aging requires its contracted agencies to conduct criminal background checks, maintain confidentiality of client records, maintain a quality improvement program, complete a minimum of 15 hours pre-service training and a minimum of three service hours per quarter of continuing education and follow an accurate plan of care that best suits the client's needs. You should always be sure that the person you care for is in a helpful and safe environment.
- ☑ **Understand what you are up against.** Learn as much as you can about your care recipient's illness, disease or condition. Consult the local branches or chapters of national organizations such as the Arthritis Foundation, the Alzheimer's Association and the Cancer Society.
- ☑ **What are the care recipient's wishes?** Keep in mind the wishes of your care recipient. If appropriate, ask for his or her input and ideas. Does your care recipient still feel good about living at home? What does your care recipient fear or dread? (These are also good questions to ask yourself).



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Caregiving Tips from the Rosalynn Carter Institute

The Rosalynn Carter Institute for Caregiving (RCI) was established in 1987 on the campus of Georgia Southwestern State University (GSW) in Americus, Georgia. The RCI was formed in honor of former First Lady Rosalynn Carter, an alumna of GSW, to enhance her long-standing commitments to human development and mental health.

- ☒ Set aside some private space. Even if it's just one corner of a room, make it yours and retreat there.
- ☒ Don't burn yourself out so much so that resentment toward your care receiver takes over.
- ☒ Find a friend or network of friends to share thoughts with. Venting is a great release of tension.
- ☒ Get plenty of sleep. Nap when the care receiver naps.
- ☒ Eat a balanced diet. You need it as much as the person you are caring for does.
- ☒ Don't do for them what they can do for themselves.
- ☒ Don't be afraid to ask for help from outside resources, then accept it.
- ☒ Ask for the care receiver's opinion or advice.
- ☒ Accept what has happened and move to improve things as they are.
- ☒ Know that you are not alone: seek a support group and learn as much as you can about the disease or disability that your loved one battles.
- ☒ Keep a positive attitude and smile. Remember you can choose what kind of day you will have.
- ☒ Don't feel guilty while taking care of yourself.



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Plan Funeral Details in Advance

No one likes to think about funerals, but both sides of the caregiving relationship will benefit if details are discussed openly.

If an open discussion is difficult, try this “love letter” as an opener:

Dear Family:

This letter is being written in hopes that the love and respect we enjoyed in life can be symbolized by the way we face death.

When we are separated by death, I fear that the grief may make the task of making arrangements more difficult for the survivors. And so, this love letter is written to ask for (or to give to you) all the relevant information that I think you need to know.

I have attached a list of topics that I think are needed (or that I think you need to know) to make this very difficult task easier for all survivors. I hope that you will consider these issues so that the next chapter will be easier for all of us. Like you, I want to respect your wishes and strengthen the bond between us.

Here are the topics that should be sent in the letter or included in a frank discussion.

- ☒ **What is in your safe-deposit box?** This is not the place for funeral instructions, insurance papers or powers of attorney that will be needed immediately.
- ☒ **How should insurance money be used?** In addition to burial, is a luncheon, or other event desired?

- ☒ **Who should be notified?** If you suspect death is imminent, please tell family members who live out of town, or ask them to check in regularly. Make a list now of names, addresses and phone numbers of people who should be contacted. You may wish to develop a second list of holiday card correspondents to whom you can send cards telling of the death after the funeral. Do not allow unpleasant memories to affect either list.
- ☒ **Write obituary notice together in advance.** Many funeral homes will agree to send the notice to local newspapers. Should memorials be directed to a particular charity or cause?
- ☒ **What type of service do you want?** Select a public, private, traditional, religious or simple memorial service. Should personal statements be allowed? Select flowers and where they should be sent after the services.
- ☒ **Who will conduct the service?** Select music, religious or literary references in advance.
- ☒ **Will you use pall bearers?** If so, make that list now. Include honorary pall bearers, if you wish.
- ☒ **Choose a Company to Handle the Arrangements.** Generally, you may choose from these options: 1. a traditional funeral home, which can offer a wide range of services; 2. an immediate disposition company, which will provide direct burial or cremation; 3. a non-profit memorial society association.
- ☒ **Choose Visitation Preference.** Whether or not viewing or visitation of the body prior to the funeral service is desired and if the casket should be open or closed.
- ☒ **What type of gathering is desired?** Make a plan to come together for a memorial event such as a wake or shivah that is consistent with the religious belief of the deceased. Do not wait until the death to resolve difference of opinion. This is not the place to discuss the disposition of the estate.
- ☒ **Make a decision about personal appearance.** Select clothing, hair style and any jewelry that should be used. (It is recommended that jewelry be removed before burial. If possible, keep a photo to be used by the funeral home; and ask if a personal hairdresser is available.)
- ☒ **What type of burial is preferred?** Select type and site of burial, casket and marker.



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Getting Your Affairs in Order

Why is it that we are such good planners for every life stage but the last? If fear disables you, think of it this way: A well-organized set of papers is one of the best legacies you can leave. Caregivers, elders and grownups in general should consider sending the “love letter” (page 4) stating their wishes and the powers of attorney (see Advance Directives #5). Planning ahead can make all the difference in the world in the event of an emergency.

Here are some things you can do to prepare:



All important papers should be organized and stored in one place.

Make sure the appropriate individuals know the location, including your spouse or another trusted family member or friend, your agent under a power of attorney, and your executor or trustees and lawyer.

- You could set up a file, put everything in a desk or dresser drawer, or just list all of your information in a notebook. Be sure to indicate the bank and location if your papers are in a safe deposit box. You may want to keep copies of some information at home because the safe deposit box will be locked at death. Check every year to see if you need to update or add new information.
 - If your information is listed on a computer, leave a record of your usernames and password(s) in a logical place so that your files can be accessed. (Most advisors suggest a paper file backup as well.)

- ☒ **List your basic information:** date of birth, social security number, names of relatives and contact information, names of agents under a power of attorney and contact information. Keep a copy of your important personal documents: adoption record, birth certificate, citizenship papers, military discharge, marriage certificate, or divorce decree.
- ☒ **Develop a list of important contacts for your service professionals:** attorney, accountant, financial advisor, human resource agents at any former employers, insurance agents, and pharmacist.
- ☒ **Other useful information includes:** bank account numbers and branch location; brokerage account numbers; credit card numbers; inventory and appraisal, title, location of personal property and keys (auto, boat, storage locker, etc); mortgage, and timeshares); insurance policies (auto, disability, health, life, property or umbrella); investments (stocks, bonds, mutual funds, IRAs, or trusts), contact information for creditors and debtors with a description or documentation of the underlying financial matter; and tax returns (income and property). If you have a dog, cat or other pet, their information (veterinary, medical conditions, medications, etc.) should be listed as well.
- ☒ **Make a copy of your:** Medicare card, other health insurance cards, and any advance directives (living will or power of attorney) or other health-related forms (list of allergies, medications, etc.).
- ☒ **Give consent in advance:** for your doctor and other service professionals to talk with your caregiver when needed. If you don't give consent, your caregiver won't be able to effectively act in your best interests. Even though some businesses may allow you to give verbal consent over the phone, it is best to give your caregiver a written authorization to protect all parties.
- ☒ **Describe any wishes regarding funeral arrangements,** including information on prepaid plan and burial plots.

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The line “Other Information” can be used to indicate important information about your house, keys, location of your important documents or even your pets.

Once you fill out this page, fold the card in half (front and back sides) and cut to size that will fit into your wallet or purse.

fold
here →

Medical Conditions _____	Current Medications _____	Known Allergies _____	Other Information _____	Organ Donor Y N	Living Will Y N	DNR Y N	Pets Y N	pacemaker Y N	hearing aid N Y	contact lenses N Y	artificial limb N Y
Emergency Medical Information											
Name _____											
Address _____											
City _____ ST _____ Zip _____											
Notify In Emergency											
Family _____						Phone _____					
Neighbor _____						Phone _____					
Physician _____											
Phy. Phone _____											
Preferred Hospital _____											



Important Resources to Know

Illinois Department on Aging: 1-800-252-8966 (Voice); 1-888-206-1327 (TTY); www.state.il.us/aging; e-mail: ilsenior@illinois.gov

Eldercare Locator: 1-800-677-1116; www.eldercare.gov

AARP: 1-800-424-3410; www.aarp.org

Administration on Aging: www.aoa.gov

Alzheimer's Disease Education and Referral Center (ADEAR):
1-800-438-4380; www.alzheimers.org

Benefits CheckUp: www.benefitscheckup.org

Children of Aging Parents: 1-800-227-7294; www.caps4caregivers.org

Family Caregiver Alliance: 1-800-445-8106; www.caregiver.org

Information About Benefits: www.illinoisbenefits.org

Illinois Department on Aging Area Agencies on Aging:
www.state.il.us/aging/2aaa/aaa-main.htm

Medicare Hotline: 1-800-633-4227; www.medicare.gov

National Family Caregivers Association: 1-800-896-3650; www.nfcacares.org

National Hospice Foundation: 1-800-854-3402; www.hospicefoundation.org

National Institute on Aging: 1-800-222-2225; 1-800-222-4225 (TTY);
www.nia.nih.gov

Social Security Administration: 1-800-772-1213; www.ssa.gov

Veterans Administration: 1-800-827-1000; www.va.gov

Well Spouse Association: 1-800-838-0879; www.wellspouse.org

Would you like to receive future Reality Check fact sheets by mail or e-mail?



Yes! Please send me future Reality Check fact sheets by mail.

Name: _____

Street Address: _____

City, State, Zip: _____

☐ Please check here if you would rather receive future Reality Check fact sheets by e-mail. **E-mail address:** _____

Please send your name and address to:

Illinois Department on Aging
Division of Communications – Reality Check
421 E. Capitol Avenue, #100
Springfield, Illinois 62701-1789

or e-mail your name and address to:

outreach@aging.state.il.us and ask to be added to the Reality Check Caregiver Resource Guide mailing list.

Thank you for your interest in Caregiving!